

News from Ed Markey

United States Congress

Massachusetts Seventh District

FOR IMMEDIATE RELEASE
March 10, 1999

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REP. MARKEY, SENS. LEAHY AND KENNEDY INTRODUCE BILL TO PROTECT MEDICAL RECORDS PRIVACY

Democratic Leaders Gephardt and Daschle Support Making Medical Privacy a Priority

WASHINGTON, DC – U.S. Representative Edward J. Markey (D-MA) today joined Senator Patrick Leahy (D-VT) and Senator Edward M. Kennedy (D-MA) in a press conference announcing the introduction of the Medical Information Privacy and Security Act (MIPSA) of 1999. Under current law, Congress must enact medical privacy legislation by August 21, 1999, or the Secretary of Health and Human Services is required to issue regulations.

Markey said, "If I were to ask you to picture where your medical records are right this moment, you probably would imagine a paper file containing the documentation of your health history which includes some of the most personal and intimate details of your life. You probably imagine this file in your doctor's office or your local hospital locked away in a filing cabinet, the keys to which dangle around the neck of trustworthy nurse who looks like your mother, the guardian of your medical records. If this is the image you are picturing, you are sorely mistaken. The time has passed when your medical records were as safe as if they were in your mother's arms -- with the stroke of a few keys on a computer or the swipe of a prescription drug card, our personal health information is being accumulated and tracked. And with such unrestricted access to one's personal health information, it's impossible to separate the **health privacy keepers** from the '**just curious**' peeper -- not to mention the **information reapers**."

"The ability to compile, store and cross reference personal health information, has made your intimate health history a valuable commodity. In 1996 alone, the health care industry spent an estimated \$10 to \$15 billion on information technology. Currently there are no laws constraining these information reapers as they delve into large data bases filled with the secrets of millions of individuals. These data bases represent a treasure chest to the information reapers and every aspect of your medical information represents a precious jewel to be mined for commercial gain!"

"Americans should have the right to say "no" to the reuse of this information."

"The Medical Information Privacy and Security Act will be the first comprehensive federal health privacy law. It will give consumers three important rights to protect their medical privacy -- rights of **Knowledge, Notice, and No**. Simply stated, individuals should have a right to full **knowledge** of who will have access to their medical information. They should have a right to be given **notice** for what purpose disclosure of their health information is needed, and they should have the right to say **NO** to disclosure of information to parties not directly involved with their health care."

MIPSA Highlights include:

- Reaffirms the fundamental right to expect that the privacy of our medical records and of the doctor-patient relationship will be protected.
- Provides individuals with the right to inspect and an opportunity to supplement their own medical record – this is currently only permitted by 28 states.
- Provides patients the right to a clear explanation of who will have access to their personal health information and why, before this information is disclosed.
- Provides patients the right to limit disclosure of their personal health information only to individuals directly involved with their health care.
- Establishes a clear and enforceable right of privacy with respect to all personally identifiable medical information.
- Creates a set of rules to govern the disclosure of personal health information and narrows the sharing of personal details within the health care system to the minimum necessary to provide care, allow for payment and to facilitate effective oversight. Special attention is given to emergency medical situations, public health requirements, medical research and law enforcement.
- Requires law enforcement to obtain a warrant for access to medical records.
- Leaves in place the current Institutional Review Board (IRB) system for federally funded research as well as extending these rules to include non-federally funded research. It also requires a review of the current IRB practice to see if improvements can be made.
- Protects the rights of states to impose even stronger standards more protective of privacy than the federal bill. This approach to preemption creates a "federal floor" and is consistent with the approach taken in all other federal privacy and civil rights laws.

Markey said, "I am pleased to stand today with my colleagues Senators Leahy and Kennedy as we introduce the Medical Information Protection and Security Act in both the House and the Senate. We have 164 days to implement a strong federal medical privacy law. Today we come one step closer to modernizing medical privacy policy for the information age.

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